1 2 UNITED STATES DISTRICT COURT 3 FOR THE NORTHERN DISTRICT OF NEW YORK JANE DOE, et al. Civil Action No.: 1:20 – CV – 0840 (BKS/CFH) 5 Plaintiffs, 6 DECLARATION OF JANE LOE IN SUPPORT OF 7 VS. PLAINTIFFS' MOTION FOR A PRELIMINARY **INJUNCTION** 8 HOWARD ZUCKER, et al. 9 Defendants. 10 11 1. I am the mother of a medically fragile child and a plaintiff in this lawsuit. I make this 12 declaration in support of the emergency relief requested. 13 14 2. Until last year, my 15-year-old son was under the care of the same pediatric neurologist since 15 he was seven years old. My son suffers from multiple diagnosed severe autoimmune 16 neurological conditions. 17 3. For the first seven years of his life, we vaccinated our son in strict adherence to the mandatory 18 schedule and included additional vaccines, such as the influenza vaccine, whenever it was 19 20 recommended. 21 Our child experienced adverse reactions after many of these vaccines, though at the time we 22 did not put the pieces together to understand what was happening. However, each time, the 23 reactions became progressively worse and lasted longer. 24 25 26 DECLARATION OF JANE LOE IN SUPPORT OF PLAINTIFFS' MOTION FOR A PRELIMINARY **INJUNCTION - 1** 27

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increased to the point of debilitation. These included, but were not limited to, having only a bite of a cracker and a sip of water a day, fears that evolved into apparent hallucinations, awaking in the middle of the night horror-stricken and raging for hours inconsolably, and numerous other debilitating severe symptoms. We were losing our son before our very eyes.

- We found a highly credentialed and respected pediatric neurologist with vast experience in helping children with John's symptoms. He evaluated John extensively, diagnosed him and treated him. He was able to stabilize certain of his neurological and autoimmune condition symptoms rather immediately, and as to other of his symptoms, more slowly and progressively, with medications, ongoing monitoring and testing, and avoidance of known triggers, such as pathogen exposures, allergens, toxins, and vaccines, to the extent possible.
- 7. Under the care and management of this uniquely qualified pediatric neurologist, John fared relatively well, compared to many with his diagnoses, as they are often homebound, unable to attend school and social/extracurricular activities. As often happens with children with John's condition, he never did make it back to "baseline" symptoms-wise and still suffers setbacks, but has been mostly functional by outward appearances, despite struggles and symptoms he strives to hide in public.
- 8. In August and September, 2012, when John first started seeing his pediatric neurologist, we were advised that further vaccinating could cause him to decompensate significantly once again. However, at that time and for the next several years he was not due for any further DECLARATION OF JANE LOE IN SUPPORT OF PLAINTIFFS' MOTION FOR A PRELIMINARY INJUNCTION 2

school-mandated vaccinations, already being fully "up to date." However, we did avoid any further annual flu shots from that point forward.

- 9. When John reached 6<sup>th</sup> grade (fall 2015), the school nurse advised that the Tdap was required to remain in school. We consulted with John's neurologist and were told he should not get any further vaccines, and completed a medical exemption which was submitted and accepted by the school nurse without issue. He also provided medical exemptions covering John for 6<sup>th</sup>, 7<sup>th</sup>, 8<sup>th</sup> and 9<sup>th</sup> grades, all of which were accepted without issue.
- 10. In August 2019, our doctor signed another exemption to cover John for the 10<sup>th</sup> grade, as the school advised that a new exemption was needed each year. We submitted the signed exemption in September 2019 along with his annual health form, as always.
- 11. Shortly thereafter, the school nurse advised us that the school district's consulting physician (a/k/a the school's chief doctor) had spoken to our neurologist's office, and was told that John "was no longer a patient there." The school nurse further advised that the chief doctor had denied the medical exemption because it had to be issued by a "treating" doctor and John is no longer treated there. Astounded, I explained that our son has been seeing this same neurologist since he was seven years old, that he's the same one that has written exemptions every year, and that he was still a patient, having been seen and treated the preceding March/April (2019). The school nurse and school doctor were unmoved and the exemption remained rejected.

12. Subsequently, we reached out to our pediatric neurologist's office repeatedly, but did not get anywhere and were virtually cut off. In email communications in reply, the response was odd and indicative of fearfulness about signing the medical exemption and words to the effect that he could not be of further assistance for John. On September 26, 2019, the neurologist followed up with a stiff letter that made no sense, given his claim weeks prior that John "was no longer a patient," stating he had just spoken with our school nurse who advised him that John needed the Tdap and meningococcal, and (astonishingly) advising that John ought have these vaccines. This was in profound contradiction with years of prior medical advice and medical documentation written to our schools about the risks the vaccines pose to John specifically.

- 13. John's last day of school was on or about September 17, 2019. We did not send him in after that point, lest he suffer the humiliation of physical ejection before his peers. On or about September 20, 2019 we received a certified letter that he was not allowed to return to the school premises or activities for lack of vaccines for Tdap and meningitis. He is otherwise fully vaccinated, including for measles.
- 14. For the remainder of fall 2019, our lives revolved around the uphill battle of trying to get John back into school and to find a new specialist. I have a full time, demanding job. There are few specialists with expertise sufficient to treat John's conditions and the waiting lists are long for all of them. John's health and academics declined dramatically in all respects.

immunologist licensed to practice in New York, who is experienced with John's conditions.

16. This doctor concurred that it would be unsafe for John to receive the Tdap or meningococcal

15. In November 2019, we got an appointment with a respected and well credentialed

vaccines. Accordingly, on or about November 14, 2019, he provided two written medical exemptions (the school adamantly insisted there had to be a separate form for each vaccine in question, which misstates the requirement of setting forth the bases as to each vaccine).

17. Months of bureaucratic delay ensued during which my son was excluded from school.

- 18. First, the school advised that the district doctor declined the Medical Exemptions because it was on the "wrong form." Our doctor's office had utilized the current New York City DOH forms, believing that to be the most currently required New York form, and we had not been able to suggest otherwise, as we were neither present while it was completed, nor aware of more than one form version (NYC vs. State). Notably, the NYC form is *more comprehensive* than the New York State form and includes all of the same information as the state form, plus a release at that bottom, which we did complete without having been asked, despite that it forces us to waive HIPAA rights.
- 19. Despite diligent efforts, I had trouble getting a response to my request for the immunologist to sign a second set of forms. Eventually, the staff told me that the doctor had received a call from someone from New York State, directing that he could not write any further New York medical exemptions "unless he was the doctor who administered the vaccinations," and that

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therefore, he would not be signing any more. Nothing in the law or regulations supports this limitation on physicians.

- 20. At our next medical appointment in early December 2019, the immunologist reiterated what the staff had said about having been admonished by New York State not to sign any further medical exemptions "unless he was the doctor who administered the vaccines." We had come prepared and showed him the text of the New York Public Health Law and verbiage from the NYSDOH site reflecting that ACIP guidelines were not the only criteria, and that he was within his rights to sign a medical exemption if he saw fit. We then asked him if, upon seeing these materials, he would agree to transfer the information from the NYC forms to the NYS forms.
- 21. Finally, he agreed to transfer what he had written on the NYC forms to the NYS forms to overcome the school's denial on a mere technicality and its request for submission on NYS forms. Again, as directed, two separate NYS forms were completed "one for each vaccine." We promptly submitted these to the school. Further delays beyond our control ensued.
- 22. Finally, on January 7, 2020, we were advised by school staff that the school district doctor denied the medical exemptions and we received written notice that John was officially stricken from the rolls and that all departments had been notified.
- 23. My son was soundly kicked out of his school and his life. His new high school friends had already long forgotten about him by now. His months in exile were extended in perpetuity and despite having slipped into despair months ago, he had now lost all hope of being granted DECLARATION OF JANE LOE IN SUPPORT OF PLAINTIFFS' MOTION FOR A PRELIMINARY **INJUNCTION - 6**

re-entry to his education and life. The impact of his school expulsion upon my son and on our family has been severe. My son is highly intelligent and well perceives that he has been forsaken, and when he tries to talk about to us as his parents or one of his doctors, in short order he begins to cry piteously. He is much worse for the wear after an entire year spent alone in his room, day after day... after day.

- 24. John's medical condition has made his life unbearable at times. A hallmark of his condition is severe social anxiety and severe school anxiety. John was just at a point of recovering enough health to make out the door each morning with minimal morning upset and was beginning to develop confidence. He was doing well in school. He was getting recognition for his music and was excited to be in several school bands. He was finally overcoming some of his social anxiety and making friends. He had conquered his first year of high school, and had a bright start to his sophomore year, and we all knew this meant he was going to make it through.
- 25. Instead, he was divested of all he had fought for his entire life a mere two weeks into his sophomore year. His confidence, progress, prospects and hope have all been gratuitously and heartlessly shattered. He has become very depressed and is not able to keep up with his home studies. While he had powered through his school struggles without an IEP or 504, the very structure of his Catholic school and the humans who dwell there, were of therapeutic import to his daily functioning. Likewise, his peers were also a source of structure and motivation, as he felt compelled to stay on par with them (or try) and to comport himself as they did in DECLARATION OF JANE LOE IN SUPPORT OF PLAINTIFFS' MOTION FOR A PRELIMINARY INJUNCTION 7

this college preparatory Catholic school. Left to his own devices, with books and a computer with a video teacher, he cannot overcome his symptoms, muster the discipline or find the purpose. Our attempts to provide therapeutic counsel or to intervene and uplift – all fall flat or worse, throw fuel on his symptomatic fire. What he wants – we cannot give him. He wants his life back.

- 26. The devastating ejection from his college preparatory high school has altered the trajectory of John's life. His college prospects are slipping away. We work full time of financial necessity and home instruction has been largely unsuccessful. He needs school with real humans to teach and care about him, and friends to draw strength and spirit from and to laugh with. Additionally, John was forced to miss the P.S.A.T. preparation and test that 10<sup>th</sup> graders take at school. He is currently in an S.A.T. prep course with his grade peers at a local private tutoring center and he is floundering far behind them, whereas previously, he had always done very well on standardized tests.
- 27. John feels hopelessly lost and his depression and anxiety have become debilitating. The stress of the situation exacerbate his medical condition and symptoms. I have been in touch with a few psychologists who can provide counseling about his situation, feelings, and homeschooling encouragement, but he refuses to engage. He insists, through tear-filled eyes, that he does not need a therapist -- he needs his life back.
- 28. He is now entering month 12 of his tragic and unjust exile. He continues to decompensate educationally, emotionally and socially. He turns 16 in less than 2 months. This age, and a DECLARATION OF JANE LOE IN SUPPORT OF PLAINTIFFS' MOTION FOR A PRELIMINARY INJUNCTION 8

year gone by "on his own," bring imminent risk of becoming ungovernable, unable to conform and submit to the rules and rituals of school, or to perceive himself as even belonging there. Occasionally, after choking on a sob that won't let him speak, he still looks at me with desperate, tearful eyes that seem to plead, "Mom, fix this," but hardly ever any more. The window is closing for him. I pray, Your Honor, please save our son.

RESPECTFULLY SUBMITTED this 21st day of August 2020

Jane Loe